



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

**ACTION:** Notice.

**SUMMARY:** In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) has scheduled a public meeting. Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATE:** August 1, 2019, 9:00 a.m. - 5:00 p.m. Eastern Time (ET) and August 2, 2019, 9:00 a.m. - 3:00 p.m. ET.

**ADDRESSES:** This meeting will be held in person and by webcast. The address for the meeting is 5600 Fishers Lane, Rockville, Maryland 20857. While this meeting is open to the public, advance registration is required. Please visit the ACHDNC website for information on registration: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. The deadline for online registration is 12:00 p.m. ET on July 29, 2019. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau (MCHB), HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of HHS (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC's recommendations regarding inclusion of additional conditions for screening, following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the August 1-2, 2019, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include: 1) review of the RUSP condition nomination and evidence review process; 2) updates on screening methodologies; 3) rare disease registries; 4) linking data resources; and 5) workgroup updates. Agenda items are subject to changes as priorities dictate. The final meeting agenda will be available on ACHDNC's website: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Information about ACHDNC, a roster of members, as well as past meeting summaries are also available on the ACHDNC website.

Members of the public will have the opportunity to provide comments. In addition to general public comments, the ACHDNC is soliciting specific feedback at this meeting from the public on

processes for nominating conditions to the RUSP condition and conducting evidence reviews. There will be time reserved on the agenda for public participants to provide comments on the RUSP condition nomination and evidence review process. Requests to offer oral comments will be accepted in the order they are requested and may be limited as time allows. Public participants may also submit written statements as further described below. To submit written comments or request time for an oral comment at the meeting, please register online by 12:00 p.m. ET on July 26, 2019. Visit the ACHDNC website for information on registration <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or area of expertise (e.g., parent, family member, researcher, clinician, public health, etc.), and the topic/subject matter.

Individuals who plan to attend and need special assistance or another reasonable accommodation should notify Alaina Harris, at the contact information listed above, at least 10 business days prior to the meeting. Since this meeting occurs in a federal government building, attendees must go through a security check to enter the building. Non-U.S. Citizen attendees must notify HRSA of their planned attendance at least 20 business days prior to the meeting in order to facilitate their entry into the building. All attendees are required to present government-issued identification prior to entry.

**Maria G. Button,**

*Director, Division of the Executive Secretariat.*

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